

The expanding role of the paediatric endocrinology specialist nurse

Kate Davies

*Senior Lecturer in Children's Nursing
London South Bank University &*

*Research Nurse in Paediatric Endocrinology
Centre for Endocrinology, William Harvey Research Institute
Barts and The London School of Medicine and Dentistry*



Disclosures

- Merck
- Ipsen
- Ferring

Introduction

- History of nursing in the UK
- Nursing stereotype
- Advanced nursing roles
- Nursing in paediatric endocrinology

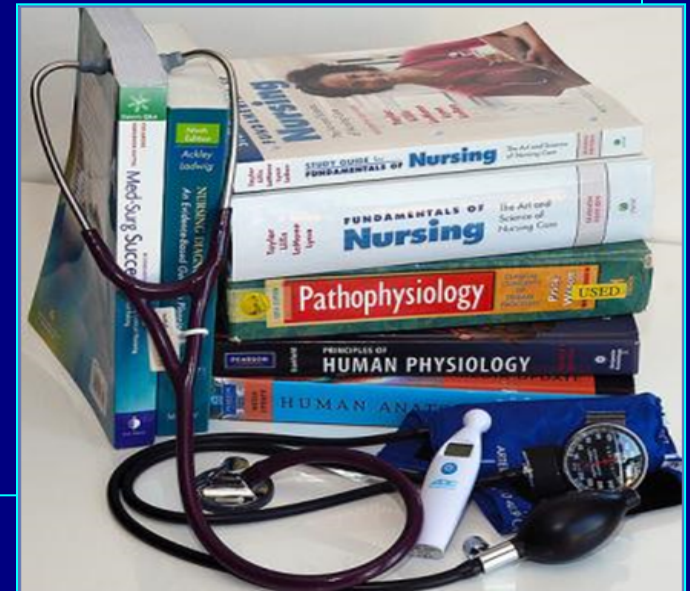


History of nursing in the UK

- First school of nursing established in 1860
- 1940s
 - State Enrolled Nurse (SEN)
 - 2 years training
 - State Registered Nurse (SRN)
 - Registered General Nurse (RGN)
 - Launch of National Health Service (NHS)
- 1960s
 - First degree in Nursing

History of nursing in the UK

- 1990s
 - Diploma 3 year training
 - Post graduate education introduced
- 2000s
 - All graduate profession
 - Training university based
 - MSc level education
 - Doctorate / Phd



Nursing stereotypes



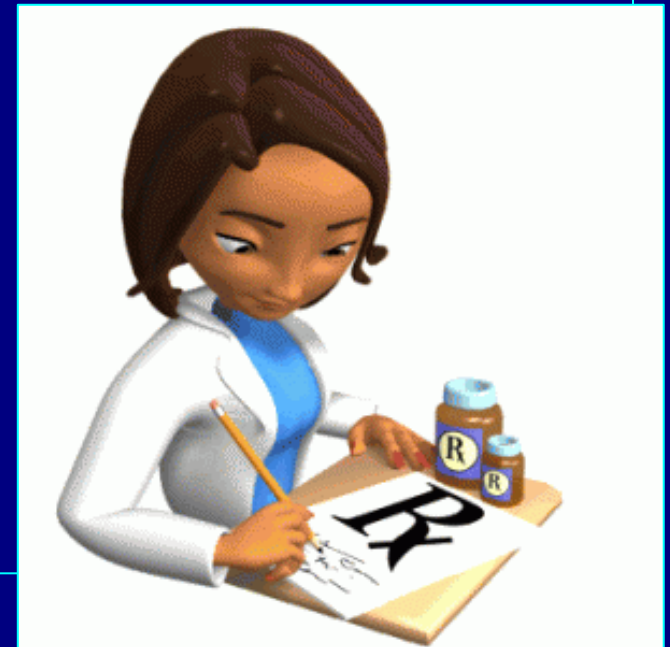
Nursing Stereotypes

- Doctors Handmaidens
 - Do nurses actually work *for* doctors
 - Training and education
 - Recruitment
 - Management structure
 - Co-workers
 - Daily care of patients
 - Liaison between patients and doctors
 - Autonomous profession

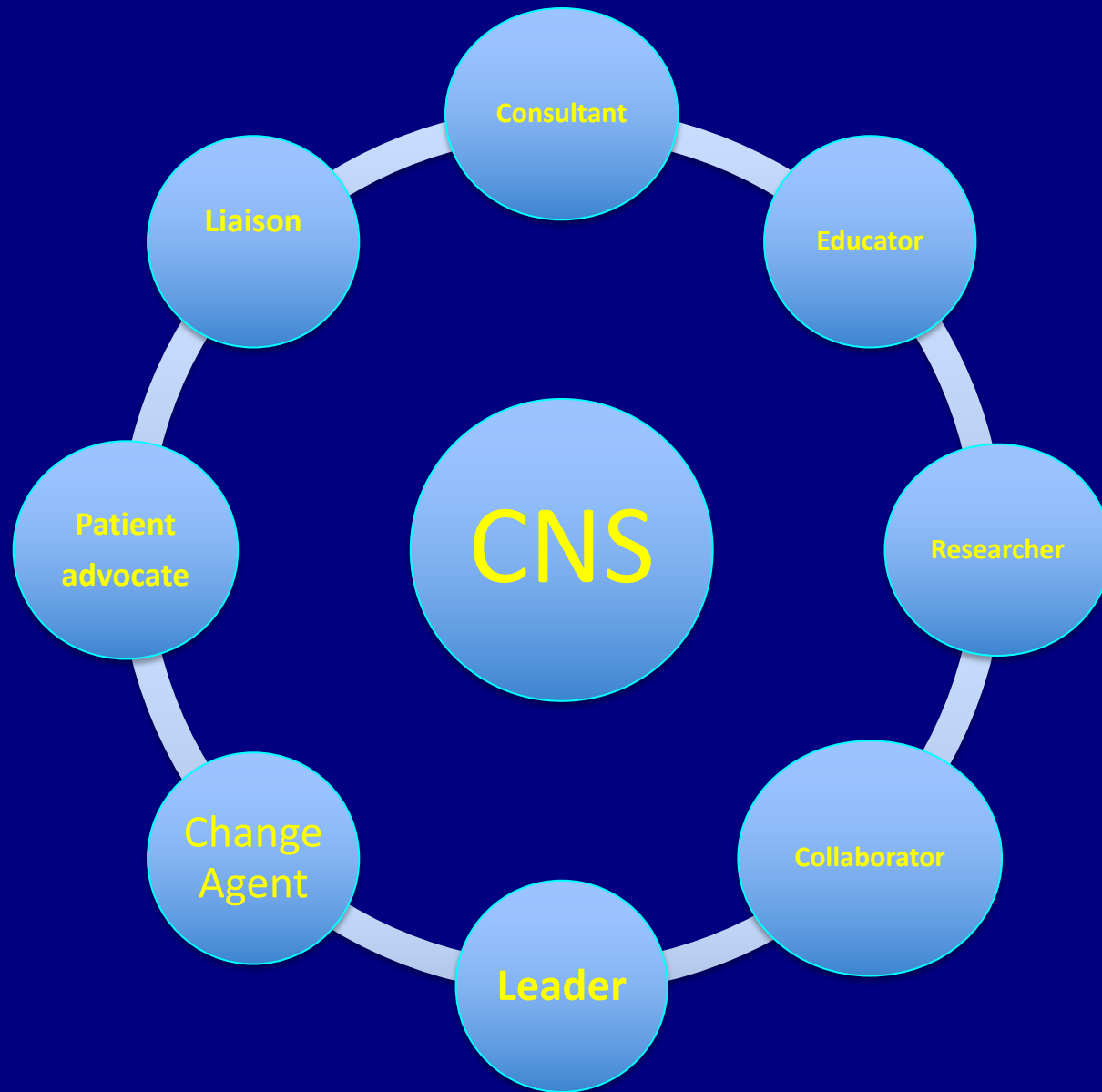


Autonomy → Advanced practice

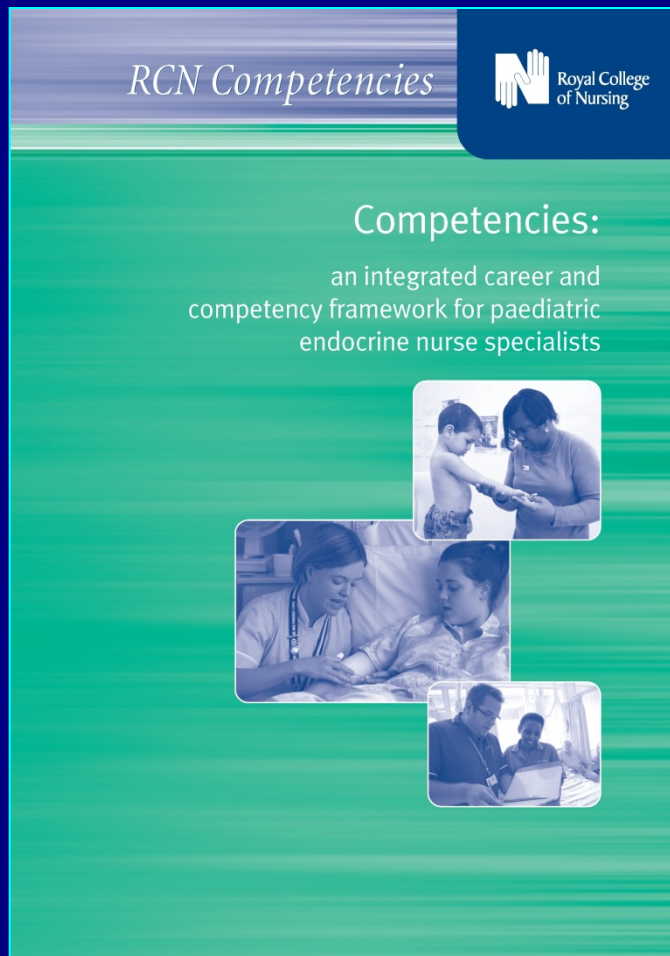
- Clinical Nurse Specialists
- Advanced Nurse Practitioners
 - Advancing roles
 - Expanding skills



Clinical Nurse Specialist roles



Guidelines for practice



- Focus on knowledge, skills and interventions specific to endocrine nurses
- References local and national guidelines
- Adheres to Benner's (1982) 'Novice to Expert' concept
 - Competent practitioner
 - Experienced practitioner
 - Expert practitioner

Education for advanced practice

- Post-graduate pathways
- BSc
- MSc
 - Children's Advanced Nurse Practitioner



Children's Advanced Nurse Practitioner

- 3 year MSc course
- Accredited by the RCN
- Specialising in specific fields





Furthering education in paediatric endocrinology

- Auxology course – St Bartholomew's and The Royal London Hospitals
 - Growth measurement
 - Bone age reading
 - Growth clinic
- BSc Module – Keele University
- BSc / MSc module – London South Bank University



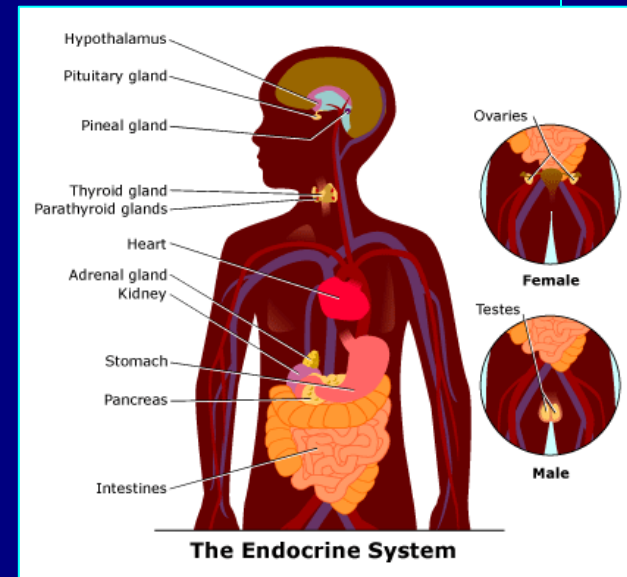
Principles of care of the child and young person in endocrinology

- Practice based assessment
 - Competency based booklet
- Formative assessment
 - Group work
- Summative assessment
 - Case study presentation
 - BSPED approved
 - January 2017



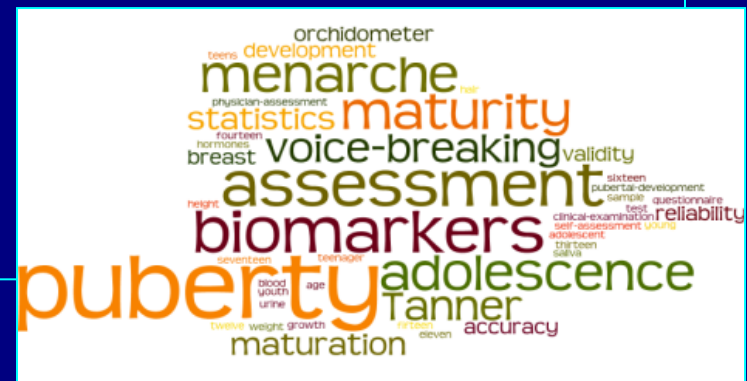
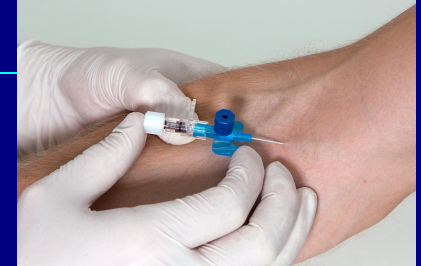
Module content

- The endocrine system
- The multidisciplinary team
- Growth and the IGF-1 system
- Puberty
- Adrenal disorders
- Disorders of Sex Development
- Thyroid disorders
- Disorders of salt and water balance
- Pancreas disorders
- Bone metabolism and bone health
- Late effects of childhood cancers
- Hormone replacement treatment
- Advanced nursing roles in paediatric endocrinology



Advanced skills for paediatric endocrine nurses

- Practical skills
 - Venepuncture / cannulation
 - Dynamic function tests
 - Physical assessment
 - Bone age assessment
- Managing own patient caseload
- Nurse led clinics



Nurse led care

- Outpatients
 - Nurse led clinics
 - Outpatients
 - Telephone
- Daycare
 - Nurse led investigations
 - GH choice and training
 - Emergency hydrocortisone training



Benefits of nurse led clinics

- Decreases patients' waiting times
 - Including the nurse led clinic
 - GH prescribing process
- Increases consultants' time for more complex patients
- Building stronger relationships with patients and their families
- Enhanced patient satisfaction

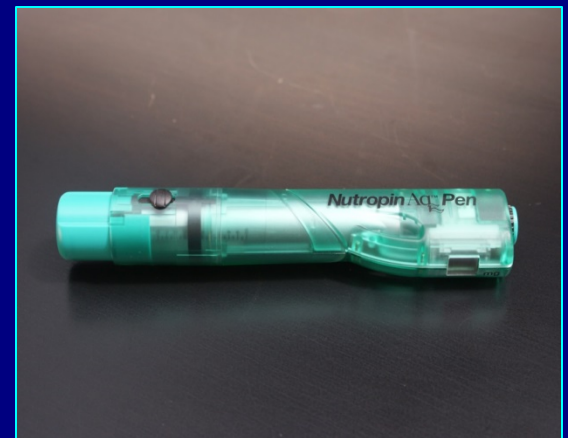
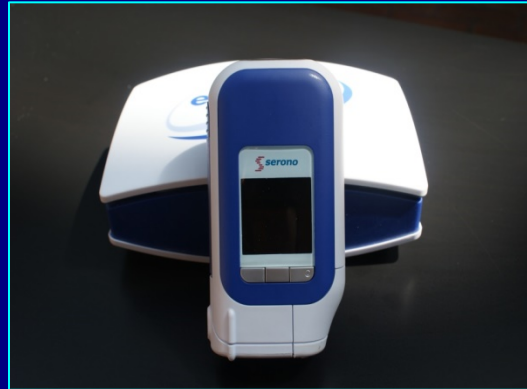


Growth hormone and the CNS

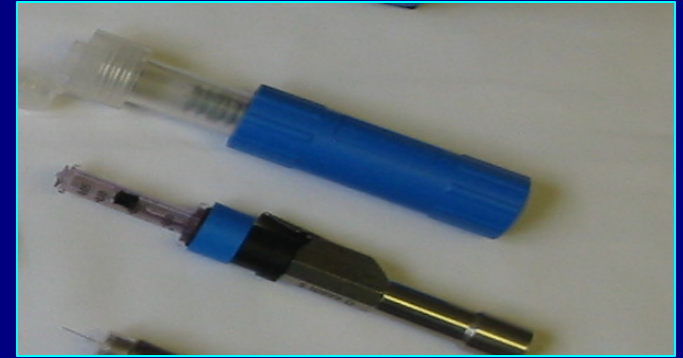
Patient choice

Concordance

GH devices



Needle free devices



Knowing our patients

- What is the CNS role in patient choice of growth hormone product?
 - Relationships with families
 - In depth knowledge about the condition
 - In depth knowledge regarding the product



Patient choice – what are the issues?

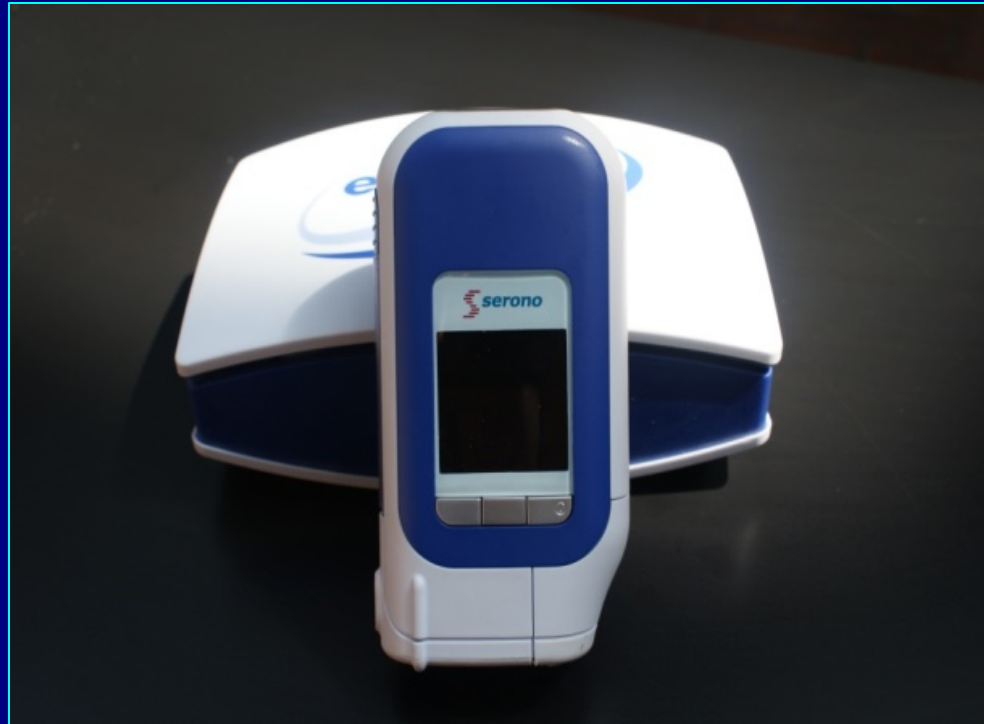
- Ease of use
- Needle free
- Colour
- Quietness
- Size
- Needle guard
- 'Feel'
- Automatic needle insertion
- Reduced time holding device against the skin post injection

Wickramasuriya, 2005

Easypod

- 'Very useful' features:
 - Pre-programmed dose feature
 - Skin sensor
 - On screen instructions
 - Display of remaining dose
 - Confirmation of injected dose
 - Automatic needle attachment

Dahlgren, 2007



Difference of opinion?

- Various comfort settings
- Dose history
- 'Teach Me' menu
- Multi-lingual instructions
- Refrigeration
- Homecare
- Reconstitution



How well do we know our patients?

- Need to understand parental perceptions and beliefs concerning illness and treatment
- Discussions of the patients' view of the disease and their expectations of the treatment
 - Shown to increase concordance

*Spoudeas, 2014; Van Dongen, 2012; Cutfield, 2011; Haverkamp, 2008;
Kapoor, 2008*

Nurse / Doctor influence?

- Do we always know what is best for our patients?
- Need a thorough, more detailed understanding
- Nurses in the prime position to know the children and their families more closely
 - Families have our contact details
 - Contact us with queries / concerns
 - Main point of liaison for families



But how does this work in practice?

- Children with learning difficulties
 - Septo Optic Dysplasia
 - Need for quick injection → Zomajet
 - Visual problems → Easypod, digital pen devices
- Teenagers
 - Something small, discreet, disposable → Miniquick
- Girls with Turner syndrome
 - Manual dexterity issues → Easypod, Zomajet
 - Larger doses needed → Easypod, Humatropen (20,24mg)
- Travelling families / children with more than one home
 - Think about non-refrigeration → Easypod, Miniquick, Norditropin

But how does this work in practice?

- SGA
 - Reduced s/c fat →
 - Want more control over administering the injection
 - No autoinjectors
 - Smallest needle, small vial sizes (4mg, 5mg, 5.3mg)
- Control taken away → Easypod
- Post oncology patients → Zomajet
- Fear of needles
 - Needle free → Zomajet
 - Needle covers / hidden needle → Easypod, Nutropin Aq, Genotropin pen and Miniquick, Nordipenmate, SurePal

How does choice work around the UK?

- Department has limited choice v.
- Free choice of all devices
 - Do we all give patient choice?
 - 89% of 52 centres surveyed do (BSPED audit 2008/2009)
- CNS
 - Chat in clinic
 - Demonstrates all devices
 - Posts out DVDs / patient literature – follow up phone call
 - Clinic appointment

Informed choice?

Nurses' roles – how to increase concordance

- Initial meeting with children and families Non judgemental, flexible approach
- Spend time with the child and family
 - Get to know their concerns and fears
 - Get the concordance agreement right
- Free patient choice of device?
- Enhanced support
- Education for patients
- Nearing adolescence
 - *Opinions on their device may change..*

Smith, 1992; Haverkamp, 2008; Kapoor, 2008; Cutfield, 2011

How can we enhance the choice process?

- ? Involve other patients
 - GH support days
 - Group demonstration sessions
- ? Courses for children for self-administration
 - Age 10 / 11
- Freedom of choice of all devices
- Explore technology
 - Text messaging
 - Apps

*Spoudeas, 2014; Van Dongen 2012;
Kirk, 2010*



Conclusion

- Paediatric Endocrine Nurse Specialists are in the best position to foster a close relationship with children and their families
- Advanced nursing roles
 - Nurse led clinics
 - Advance patient care with more time
 - Educate the children and families more on their condition, and about GH devices
 - Get to know the families and the implications of their conditions
 - More and more CNSs becoming Independent Prescribers and Advanced Nurse Practitioners

Are we the future...?